



New Jersey Department of Children and Families Policy Manual

Manual:	CP&P	Child Protection and Permanency	Effective Date:
Volume:	V	Health	
Chapter:	A	Health Services	11-29-1994
Subchapter:	6	End of Life Care	
Issuance:	100	End of Life Care	

Philosophy 11-29-94

All children are entitled to receive available and appropriate treatment and services which are necessary to address their health care needs. When a CP&P supervised child is suffering from a terminal illness, condition, or disease, CP&P has a responsibility to ensure that appropriate steps are taken in order to access necessary health care and to work with the various components of the system to access other services which will optimize the child's quality of life.

Children under CP&P supervision, regardless of placement status, are entitled to health care and support services which, together, will maximize the ability of the child's caregivers (i.e., parents/ guardians, family, substitute care providers, medical/health care personnel) to manage the child's care in a manner which is the most comfortable, age-appropriate, and pain-free for the child.

Also see [CP&P-V-A-7-100](#), Health Considerations for Adolescents.

Life-threatening or Terminal Illness or Condition 11-29-94

A terminal illness, condition, or disease is a medical condition for which there is no likelihood of reversing or stopping its natural course.

Some examples of illnesses which may be terminal are cancer, cystic fibrosis, AIDS, Tay-Sachs disease, anencephaly.

Discussion of Child's Condition 11-29-94

a. Physician's Discussion with the Parent

Once a diagnosis has been made, it has been confirmed that the child's condition is terminal, and a prognosis for the manner in which the condition will likely proceed has been determined, the child's physician is responsible for discussing this information with the parent. The physician explores with the parent the parent's understanding of the child's condition. The physician discusses the

recommended course of treatment and the possible types of treatment, medication, therapy, etc., that have been prescribed or ordered for the child. These may include chemotherapy, pain control medication, special nutrition, ventilator assistance, palliative care, radiation therapy.

b. Hospital Bioethics Committee

Each hospital has a multi-disciplinary standing committee whose purpose, in part, is to:

- participate in the formulation of hospital policy related to bio-ethical issues;
- participate in the resolution of patient-specific bio-ethical issues;
- provide a forum for patients, families, and staff to discuss and reach decisions on ethical concerns relating to patients. N.J.A.C. 8:43G-5.1.

Additionally, each hospital is required to have policies addressing bio-ethical issues affecting individual patients, including, at least, removal of life support systems, discontinuance or refusal of treatment, and designation not to resuscitate. N.J.A.C. 8:43G-5.2.

When there is a need for discussion of ethical concerns relating to the child's medical care due to:

- a conflict between the parent/caregiver and health care providers;
- a conflict between the health care providers responsible for the child's care; or
- when there is a need to discuss whether life support should be instituted, continued, or discontinued,

it may be helpful for the parent/caregiver or other concerned person to bring the issue to the bio-ethics committee for their discussion, input, and assistance in making an informed, appropriate and acceptable decision.

c. Worker's Discussion with the Parent

Whenever the Worker has been made aware that a child has been diagnosed as being terminally ill, that information is shared with the Nurse Consultant in order to make a determination as to whether short-term or on-going services by the Nurse Consultant will be necessary. The Nurse Consultant may need to contact the child's physician and other primary medical providers in order to confirm the diagnosis and prognosis, to discuss what care/treatment is planned for the child, and to review what the physician told the parent. The Nurse Consultant may also

wish to contact those persons who will be providing and coordinating primary service to the child and family. This information is then shared with the Worker.

It may be helpful for both the Worker and Nurse Consultant to make an initial joint visit to the home to review with the parent the physician's discussion in regard to the child's diagnosis and to assess the parent's understanding of the child's condition and diagnosis and the ability and willingness of the parent to cooperate and, as necessary, carry out the plan for medical care and treatment. They may also explore with the parent whether there are relatives or friends who can help with the child's care or provide other assistance, e.g., grocery shopping, baby-sitting for siblings, housekeeping, transportation.

While it is clearly necessary to discuss the fact of the child's terminal condition and to be as forthright as possible about the prognosis and the care and treatment the child will be receiving, it is very important that sensitivity to the parent's need for denial, distancing or other psychological means of trying to cope with the illness be maintained. Support for the emotional needs of both the child and his caregivers is a necessary component of service provision during this stage, and may sometimes be the most difficult to address.

With the agreement of the parent, the Nurse Consultant and/or Worker can help the parent to discuss the child's condition with other primary caregivers, relatives, or siblings (as appropriate). The Nurse Consultant and Worker can offer to make referrals to support groups, therapists, etc., and arrange appointments if the parent is interested in receiving these or other services for himself or for other family members, such as siblings, who may also benefit from such services.

The Worker should maintain contact with the parent in order to:

- provide support;
- help the parent acquire as much information as necessary for him to understand and cope with his child's condition;
- be able to contact or facilitate contact with the parent when consent is needed in order to perform certain medical procedures or treatment; and ultimately,
- help the parent make plans and decisions when the child is approaching death.

Other Person Acting In Loco Parentis

11-29-94

Information should be gathered from the parent (if it has not already been done) regarding the names and whereabouts of other relatives who may be willing and able to assume parental responsibilities should the parent become unavailable or missing, particularly during the final stages of the child's illness. The Worker should clearly explain the importance and necessity of there being someone who

has the authority to act on behalf of the parent should it become necessary. Discussion should include ascertaining whether there is a particular relative or family friend who the parent would trust to make decisions for the child's care in his (the parent's) absence. If the parent is able to identify someone, that person should be contacted to assess his ability and willingness to assume decision-making authority for the child. If he is able and willing, a meeting should be arranged for the parent and the relative/friend. The discussion should be clearly documented in the child's case record. The Nurse Consultant, if involved in the child's case, should be apprised of the results of the meeting.

If the parent is missing at the time the child is diagnosed as being terminally ill, relatives should be contacted immediately in order to determine whether they have any knowledge of the parent's whereabouts; any leads should be followed by the Worker. At the same time, any relative (or other appropriate person) who is willing and able to assume responsibility for decision-making or caring for the child should be assessed and the discussion noted above should occur (in the parent's absence) if he or she appears to be an appropriate resource.

Consideration should be given to encouraging the relative/other person to file for custody of the child so that medical consent forms, including consents for DNR orders, can be signed as the need arises. Resource parents, cannot consent to DNR orders.

See [CP&P-III-C-4-100](#) for policy and procedures in regard to identifying and searching for parents and relatives.

Discussion of Do Not Resuscitate Orders 11-29-94

At some point in the physician's discussions of the child's condition and treatment, the subject of the risk or likelihood of the child's suffering cardiac or respiratory arrest will need to be broached with the parent or designated person if the parent is not available. While it is important for the discussion of cardiopulmonary resuscitation to take place when it is clear that the child is terminally ill, it is particularly important that the issue of the parent's consent to a DNR order be discussed by the physician with the parent as soon as it is apparent that the child is nearing death or that his condition is seriously or rapidly deteriorating.

Cardiopulmonary resuscitation efforts may or may not be appropriate or acceptable depending upon the current health of the child, length of life expectancy, and parent's personal preferences. While such efforts may prolong the child's life, they may also result in death or deterioration of the child's condition. The physician is responsible for a thorough discussion of the possible results of resuscitation including:

- whether the child's condition will be the same or will become significantly worse,

- to what extent the quality of the child's life may be adversely impacted, and
- whether resuscitation will be beneficial or whether it will be futile and not in the best interests of the child.

If the child's condition is such that attempts at resuscitation would be futile and not expected to restore cardiac or respiratory function, the physician may ask the parent to consent to a do not resuscitate (DNR) order. If the parent is in agreement with the physician, the order is written and placed in the child's medical record. DNR orders are time-limited and expire, usually within 7 to 14 days. Therefore, they must be periodically reviewed and updated. The physician should advise the CP&P Worker so that the information can be documented in the case record as well. If CP&P has not been contacted by the physician or other hospital/hospice staff, the Worker initiates the call to the physician to verify the existence of a signed DNR order.

See [CP&P-V-A-1-250](#) Policy Regarding Do Not Resuscitate Orders.

Children in Out-of-Home Placement 11-29-94

The parent of a child who is already in out-of-home placement or who enters out-of-home placement after he has been diagnosed as being terminally ill must be strongly encouraged and assisted to maintain close contact with the child and with those providing care and support to the child, including CP&P. The Worker should suggest that the parent maintain contact with the child in the form of letters, cards, drawings, telephone calls and visits.

To the child who is able to understand the significance of his illness and diagnosis, such contact may be all the more important by providing the parental strength and comfort so crucial to the child's quality of life and his ability to cope with, not only the symptoms of his illness, but with his mortality. His feelings of being abandoned, i.e., being placed out of the home, may be compounded by feelings that his illness contributed to his being placed or that he is in some way responsible for his illness.

If it is in the best interest of the child, periodic discussion of the return home of the child should take place to ensure that the parent understands that the child may be able to return given appropriate support services. However, if it is clearly not in the child's best interests to return home, discussion should focus on the parent's maintaining contact with CP&P, the child (if appropriate), and the child's physician in order to maintain the case plan and to be available to sign consents for medical treatment or other procedures.

Resources and Services 11-29-94

a. Coordination

So that the child and his family/caregivers are provided with all necessary and appropriate services, it is critical that all efforts are carefully coordinated. Determination of appropriate resources and supports for the child is made by the Worker, Nurse Consultant, child's physician, and/or, when applicable, the DMAHS Office of Home Care Programs (for children on waiver programs). Although each person plays a different role, the collective goal is to ensure that an integrated plan of care is developed, implemented and maintained for the child and his family/caregivers.

The parent/caregiver should be involved, to the extent necessary and possible, in the discussion of resource use. He should be provided with the opportunity to ask questions in regard to the conditions required for service provision by the identified resource(s), and to express his feelings in regard to resources or supports which he feels will or will not help him, the child, and others closely involved to cope with their situation.

b. Choice of Resources and Services

The choice of a resource or service is dependent upon the child's illness/condition, current needs of the child, family, or other caregivers, availability of the resource, and the child's care requirements.

Resources and services can include, but are not limited to:

- homemakers,
- personal care attendants,
- hospice care,
- child care,
- support groups,
- transportation,
- visiting nurses,
- respite care,
- environmental modifications,
- health care equipment,
- therapy, e.g., physical,
- psychological, occupational,
- home health aides.

Services and supports are arranged and provided as needed including consultation with an Office of Child and Family Health physician.

The child's family, including siblings and family friends, are important sources of personal comfort and support to the child. The family is defined as relatives, caregivers, and/or other significant persons who provide physical, psychological, social and/or spiritual support for the child.

Staff at the hospital/clinic in conjunction with the CP&P Worker coordinate/arrange services as ordered/requested by the child's physician. Additionally, other services/supports determined to be appropriate when requested by the family/caregiver or when determined to be appropriate by the CP&P Local Office Child Health Unit Nurse or CP&P Worker may be arranged.

Hospital Care vs. Hospice Care 11-29-94

A terminally ill child may experience a number of hospitalizations as a result of his condition, but may have been receiving testing and treatment primarily on an out-patient basis. The choice of where the child's end-stage care will take place, i.e., in a hospital or hospice facility or at home under the supervision of a hospice program, must, at some point, be discussed by the physician with the parent/guardian. This discussion may need to be repeated at a later date by the physician and the CP&P Worker as the child's condition changes or the parent's/guardian's feelings toward the type of care or treatment change.

a. Hospice Care

Hospice care is comfort-oriented palliative care of a patient with a terminal illness or condition rather than treatment aimed at cure. Hospice care is not euthanasia (mercy killing) or assisted suicide. It is care meant not to hasten or postpone death, but rather to manage the patient's care as well as possible until death. Hospice care, whether in a hospice facility or in the child's home, is a concept of providing holistic care for the terminally ill child and the family. Its focus is to maintain the patient as pain free, alert, and comfortable for as long as possible and provides a continuum of care from admission to a hospital or hospice program through bereavement services.

Hospice care is usually provided to the child in his home or resource home, although it may be provided in a hospice facility. The hospice may be a "free standing" facility or it may be a part of a hospital or similar facility which espouses the hospice philosophy and provides hospice services. A hospice facility is usually able to provide a more home-like setting and may allow for easier accessibility to the child by family and friends than would a typical hospital setting.

In-home hospice care requires the consent and cooperation of the parent and the child's physician. It also requires that the parent, a family member, family friend, or other caregiver (such as a resource parent) is willing and able to act as the

primary caregiver for the child; however, such care may be supplemented by, e.g., a homemaker, personal care attendant, volunteers, VNA.

Wherever the end-stage care of the child takes place, professional health care providers are involved in the provision of care to the child either directly (in a hospice facility) or through the supervision and support of the primary caregiver in the child's home. These include the child's primary physician, hospice program primary nurse, hospice program social worker, as well as other hospice program staff such as the chaplain, bereavement coordinator, home health aides, LPN's, and volunteers. In addition to medical care and related support services, the hospice program may provide equipment and supplies, counseling, training for caregivers, and respite care.

Life sustaining treatment (also known as life support) is not within the hospice philosophy. Examples include ventilators, cardiopulmonary resuscitation (CPR), and dialysis. That is, no medical procedure, intervention, technology or administration of medication (other than pain medication) is administered to a patient in order to forestall the moment of death.

Therefore, if the child is enrolled in a hospice program and the hospice program has required consent for a do not resuscitate (DNR) order, the hospice staff will not attempt efforts at resuscitation. Such a requirement does not prohibit the child's family from changing its mind and withdrawing consent to the DNR order. It should be noted that if the DNR consent is withdrawn, the hospice program may discharge the child.

If the child suffers cardiac or respiratory arrest at home or in a hospice facility which did not require DNR consent as a requirement for enrollment and the parent continues to be unwilling to sign a consent for a DNR order, staff at the facility or the paramedics who are called to the home will make resuscitation efforts.

Hospice programs generally have standard provisions for pronouncing a child dead when the child has died at home. Therefore, when the child dies at home, the death needs to be witnessed by a nurse who then can pronounce the child dead. The body may then be taken directly to a funeral home rather than to the hospital. The hospice staff is responsible for making provisions for notifying the child's physician and local police department. The police department is generally provided with the name of the child's physician or hospice program contact and an explanation of the child's circumstances so that when death occurs, there will be no unnecessary concern that it was the result of child abuse/neglect.

b. Hospital Care

The primary difference between hospital and hospice care, particularly hospice care in the home, is that in a hospital the care provided refers to the traditional practices of caring for terminally ill patients in an effort to keep them alive for as long as possible. Such care is provided by professional caregivers such as

physicians, nurses, therapists, technicians. When the child receives all of his care in a hospital, it is a given that the child is not among family and familiar surroundings, and has more limited access to his family, belongings, pets and other emotional comforts.

For some children and their families, however, hospital care may be the appropriate choice. Hospital care may be preferable when the following, or similar, circumstances exist:

- parents who are unable or unwilling to assume intensive, often complicated, caregiving;
- parents who feel they cannot deal with having the child die at home;
- parents who are dysfunctional due to, e.g., substance abuse, mental illness, physical illness, marital/civil union problems;
- families in which there are many children who require much of the parent's attention;
- there are no relatives or other caregivers willing and able to accept responsibility for the child and his care;
- homes which cannot be environmentally modified to suit the child's needs; or
- homes which are not accessible to hospice services due to geographic location.

Stress on Parents and Caregivers 11-29-94

Once the child has been diagnosed as having a terminal illness, the parent typically experiences many emotions including:

- guilt: i.e., how, why did I let this happen; what did I do; parent feels a sense of failure;
- anger: parent may be angry at himself, the other parent, the illness, society, and even the child;
- shame: particularly with diagnosis of AIDS, parent may feel that illness is a stigma;
- denial: the parent denies that the child is terminally ill and will die;
- depression: the more the illness/disease, especially AIDS, is a secret, the more the diagnosis becomes a burden; may cause paranoia; may feel self-pity, concern about maintaining a job, home;

- loss of control over illness: parent may feel as if he wants to give up, may feel he can't do it anymore; may lose control, cry, feel overwhelmed; or, the parent may overcompensate by demanding that things be done in a particular way, become overprotective of the child; and
- shock: how could this happen;
- bargaining: often with God, e.g., if you don't let my child die, I'll become more devout; if you don't take my child, you can take me instead;
- acceptance: parent accepts diagnosis usually after having gone through other stages, but acceptance can come at varying times.

Therefore, for the sake of both the parent and the child (as well as other closely involved persons), the parent should be supported to the greatest extent possible through linkage with hospital or hospice support programs and services and/or through catastrophic care, disease-specific support organizations.

Emotional Impact of Illness on the Child

11-29-94

The extent of the emotional impact of knowing that he or she is terminally ill depends on factors such as the child's age and developmental level, which in turn, affect the child's understanding of life and death, sickness, health, God or other religious concepts.

Older children usually want to be informed about the specifics of their health status and to be involved, to the extent possible, in making decisions about their care and treatment. They generally have the verbal ability to describe or express their feelings and to ask questions directly related to what is happening to them.

Teenagers, while having the verbal ability, may, instead or in addition, become uncontrollable, non-compliant, and attempt to sabotage their care and treatment. Because they are in the process of developing a self-image and finding their place in the world, the physical effects of treatment (e.g., hair loss, disfigurement) may become obstacles to cooperation.

Discussion of the facts and effects of the illness upon the child with the child himself is a complicated, highly sensitive task best left to those who have been specially trained to do so. The child may be told of his diagnosis and prognosis by the parent or caregiver with the assistance, if the parent desires or circumstances dictate, of the child's physician, or a nurse, hospital social worker, or other trained person who has been closely involved with the child. While the Worker can visit with the child and listen to what the child is expressing, it is not advisable to attempt or encourage in-depth discussion of the child's illness or medical treatment. Hospital and/or hospice staff will arrange or provide support services to address these issues with the child either through support groups, individual counseling, or both.

If the child wishes to be involved in planning for his funeral and burial services or other activities related to his death (such as giving certain personal articles to friends or siblings), the Worker may help the child to do so. See *Services to Prepare the Terminally Ill Child and His Caregivers for the Child's Death*.